

Good Afternoon, my name is Kathleen Kelly and I am the Executive Director of the Family Caregiver Alliance in San Francisco. It is an honor to be here to address this Senate Forum today. I am especially pleased to participate in a national discussion which is examining not just the needs of family caregivers, but models already in place at the state level to assist families who care for loved ones with chronic illnesses and disabilities. In particular, my role here is to describe Family Caregiver Alliance (FCA) and its affiliate system of Caregiver Resource Centers (CRCs) in California.

How Did Family Caregiver Alliance Begin?

Family Caregiver Alliance (FCA) began as a grassroots effort by a small group of San Francisco families and concerned professionals during the mid 1970's. The plight of one local woman, Anne Bashkiroff, helped launch California's statewide service system. In a time before Alzheimer's disease was a household word, Mrs. Bashkiroff struggled in her own private hell trying to understand and meet the enormous care demands of her husband who, following surgery and high fever had become confused, disoriented and unable to work. Mr. Bashkiroff received a diagnosis of "pre-senile dementia" from a neurologist-and Mrs. Bashkiroff received the news that the disease was progressive, untreatable, and beyond the scope of the neurologist's practice. She returned home with her husband and suffered through the full spectrum of emotional, physical, and financial despair now familiar to millions of **Americans who have viewed documentaries** and other public awareness efforts on Alzheimer's disease.

In 1976, a community volunteer learned of Mrs. Bashkiroff's unsuccessful efforts to locate a nursing facility for her husband and offered to bring Mrs. Bashkiroff's story to a local mental health organization. Upon hearing Mrs. Bashkiroff present her case, a task force, calling itself Family Survival Project, was convened to examine the problem of middle income families coping with chronic care for adults with irreversible brain impairments. Families like the Bashkiroff's were confronting similar situations elsewhere, and many were seeking help from over-stressed health, mental health, and social service providers. But the approach chosen by the task force to respond to problems in San Francisco was unique in the United States.

The task force consisted of family members with relatives who suffered from a variety of brain disorders (e.g., degenerative dementing illnesses, aneurysm, Parkinson's disease, and traumatic brain injury). Other task force members included an attorney, a psychotherapist, and a psychiatrist. In 1977, the task force sponsored a community meeting receiving considerable press attention both locally and nationally. Additional meetings were held with agency administrators and public officials. The public attention drew hundreds of inquires from throughout the U.S. and Canada. As a result, public officials informed the task force that the problems they were attempting to address would extend far beyond the abilities and jurisdictions of local service agencies.

Drawing on broad grassroots support generated by their public awareness activities, the task force members began calling on officials in the State Capitol and in Washington, DC. The result was a special grant in 1978 through the California Department of Mental Health to determine the number of individuals with adult-onset brain damage and available services; to establish a support network of families and conduct a public awareness campaign; and to publish a handbook on legal and financial information. Among the most significant task force findings was the dearth of services available for families caring for brain impaired adults.

The task force got support from a local state legislator (former Assemblyman Art Agnos) to sponsor

legislation (AB 1043) to pilot test a model of support services dedicated to families caring for a loved one with an adult-onset brain impairment (e.g., Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury). FCA applied for the pilot project funds after the legislation was enacted and was awarded the contract in 1980. Under the administration of the California Department of Mental Health, the pilot project, which developed a core package of family caregiver support services, was tested for three years. At the end of 1983, the pilot project was deemed to be a success and had documented an extensive need for a coordinated, comprehensive, and affordable service package for family caregivers.

FCA then asked Mr. Agnos to introduce legislation (AB 2913) that would accomplish two major goals: 1) *Regional Services*. The location of resource centers similar to FCA's pilot program in each major geographic region throughout the state in order to provide a single-entry information network; and 2) *Statewide Coordination*. The establishment of a Statewide Resources Consultant role for Family Caregiver Alliance, under contract to the state, to oversee aspects of the new law that were statewide in nature. The resulting landmark legislation was called *The Comprehensive Act for Families and Caregivers of Brain Impaired Adults* (Chapter 1658, 1984 California Statutes, as amended).

The new law was passed in 1984 to establish a statewide system of Caregiver Resource Centers (CRCs) which replicated FCA's pilot project. Over a period of four years, 10 additional Caregiver Resource Center (CRC) sites were phased-in so that in 1989 a full complement of 11 CRCs were designated in all regions of the state. All CRCs are non-profit organizations under contract to the Department of Mental Health and all are modeled after the San Francisco pilot project. Moreover, Family Caregiver Alliance (formerly Family Survival Project) as the original Caregiver Resource Center was given an additional role under the new law to serve as the Statewide Resources Consultant (SRC). In this capacity, the SRC assists the Department of Mental Health in statewide program development, data analysis and reporting functions, and technical assistance to the 11 CRC sites. The SRC also operates an information clearinghouse on adult-onset brain impairments and caregiving issues, conducts education and training, and carries out applied research.

The Range of CRC Services

Today, the CRC system provides an array of caregiver support services including:

Specialized Information advice and referrals to help families understand the nature of a brain disease, prognosis and how to cope with functional and behavioral problems associated with brain disorders. Basic information is also provided on legal and financial issues, long-term care planning, and community resources.

All family caregivers who require assistance beyond basic information receive a uniform **assessment** administered at the family caregiver's home. Assessment methodically and uniformly identifies and records specific caregiver problems and assists both the CRC staff and the caregivers in determining the most appropriate type and mix of services. Assessment seeks to: determine the care recipient's functional problems; determine perceived burden, that is the extent to which caregivers' personal, social and emotional well-being is affected by caregiving; determine the impact of caregiving on the caregiver's physical and mental health; and collect demographic data to develop a statewide database on caregivers and brain impaired adults. Once the assessment is completed, the CRC staff work with the caregiver to develop a care plan for the most appropriate type and mix of CRC family support services, based on the caregiver's identified service needs. Caregivers are reassessed at six-month intervals as long as the need for assistance continues.

Family Consultation is used to help caregivers develop and implement a personalized care plan. CRC

staff, called "Family Consultants," assist families in making difficult decisions, problem-solving, and coping with stress. Through family consultation, caregivers learn how to manage difficult behaviors in the persons they care for, how to make their homes safe for their impaired relative, and practical skills (e.g., for lifting or bathing a nonambulatory person). In addition, caregivers learn strategies to cope with their frustration, anger, or isolation.

For those caregivers shown to have high levels of depressive symptoms, CRCs provide **short-term counseling**. Under the leadership of FCA, the CRC system has developed a six-session structured counseling protocol which helps caregivers address psychosocial issues related to the caregiving role (e.g., feelings of hopelessness, guilt, or anxiety). Depending on the needs of the family caregiver, trained licensed clinicians help caregivers to "work through" difficult issues such as role reversal, sexuality and intimacy with a demented spouse, or fears/guilt associated with the move--or possible move--of a loved one into a nursing home.

One-time **legal consultations** are used to help families sort through complex legal and financial issues including surrogate decision-making and advance directives, conservatorship, estate planning, and public benefits eligibility. CRCs subcontract with attorneys specializing in eldercare and estate planning to help families prepare durable powers of attorney for health care (DPATIC). When possible, advance planning can save families time, money and heartache by avoiding a costly and time-consuming court-ordered conservatorship process.

Education and training events are useful vehicles for promoting public awareness and reaching caregivers in their own communities to provide caregiver-specific training. Training events are conducted regionally throughout the state as a means of educating families about the course of a disease, care techniques, current biomedical research breakthroughs, legal planning issues, long-term care options, and self-care/ stress reduction strategies. Annual rural trainings on Alzheimer's disease bring current research and other information to underserved rural communities and individually-tailored trainings are conducted for professionals, volunteers and allied health providers, such as nursing home staff and home health aides.

CRCs sponsor **support groups** for families, caregivers and brain-impaired adults, such as concurrent groups for individuals with early-stage dementia and their caregivers, a peer group for brain injury survivors, and an on-line caregiver support group through the FCA website. In addition, a number of the CRC sites conduct **psychoeducational groups** which are structured eight or ten-session classes used to teach caregivers skills to manage anger or frustration.

Respite care for families offers financial assistance for a flexible array of respite service options. Monthly respite vouchers are provided through subcontracts with local home care agencies, adult day programs, or facilities offering overnight respite. Or, families may choose a direct pay option, where they receive a cash subsidy (capped at \$425 per month) to hire an independent provider to provide in-home respite care. The CRC respite program maximizes consumer choice by letting families select the option(s) which best fit their needs. In addition, CRCs across the state sponsor periodic weekend respite "camps" and retreats, often targeting families on their respite waiting lists.

How Was The Service Need Identified?

As mentioned earlier, a San Francisco Task Force was formed in 1977 to more closely examine the problem of adult-onset brain disorders. Among the charges of this pioneering group was to determine the incidence and prevalence of individuals afflicted with brain-impairing conditions and to develop a support network of families. A task force report highlighted the difficulties of obtaining any reliable

estimates on the number of people affected. Differing nomenclatures used to describe dementing illnesses, inconsistency in medical data reporting, and the lack of any registries to record diseases like Alzheimer's made incidence and prevalence figures elusive. The report also identified significant service gaps for brain impaired adults and their families. While service systems were in place for children and adults with developmental disabilities, as well as for persons with mental health and psychiatric problems, no services existed for those with adult-onset organic brain disorders. Moreover, in the late 1970's no services existed to address the needs of the family caregiver and the support required to assist with what has since been termed the "36-hour day."

The Function Of Family Caregiver Alliance As It Pertains To State Services

FCA's mission is to support and assist families and caregivers through education, services, research and advocacy. Our goals are to: 1) serve as a leader in health and long-term care services, education, research and advocacy. 2) Develop, implement and evaluate leading edge programs which respond to the ever-changing needs and characteristics of caregivers in the community. 3) Advocate for inclusion of family caregivers and adults with brain impairments in health and long-term care policies. 4) Uphold quality and effectiveness of direct services, education and information. 5) Generate a strong resource base that enables more caregivers to be served.

Governed by a 14-member Board of Directors, a staff of 24, and technical consultants for specific projects, FCA undertakes a wide variety of activities in support of caregiving families in six counties of the greater San Francisco Bay Area and statewide. Current activities include those under the two contracts held with the Department of Mental Health for regional and statewide services: The Bay Area CRC (direct services for caregivers, education and program development), and the SRC (technical assistance, education and training, research, information management, clearinghouse). Other FCA activities funded by private foundations and corporations include weekend respite camps, specialized educational events (e.g., a 1997 conference on genetics and ethics); and applied research on decision-making and consumer-directed care (funded by The Robert Wood Johnson Foundation).

At the state level, in addition to serving as the model program to create the CRC system, FCA staff have participated on the California Workgroup on Alzheimer's Disease Management Guidelines (1997-98); In-Home Supportive Services Agenda Coalition (1997-98); Medicaid Blue Ribbon Committee, California State Senate (1996); Elder Care Advisory Committee, State of California Little Hoover Commission (1996); Technical Advisory Committee, California Public Interest Center on Long-Term Care (1994-97); Health Access Coalition Steering Committee (1991-95); California Interdepartmental Committee on Aging (1986-97); and California's first Alzheimer's Disease Task Force (1985-87). In cooperation with DMH and the CRCs, FCA sponsored four public forums across the state for the 1995 White house Conference on Aging; sponsored the first working conference on respite policy in California (1992); testified many times before legislative committees on the needs of family caregivers; prepared commissioned policy research reports; and serves as a credible, timely source of information on caregiver issues for state policy makers.

Patterns In Participation, Family Needs, And Program Growth

Key findings from the CRC statewide assessment database are as follows:

- The typical caregiver is 60 years old, female (76%), and most likely a wife (33%) or an adult daughter (31%).
- The typical care recipient is a 75 year old male who has suffered from Alzheimer's disease for an average of nearly 5 years.

- Both the caregiver and the care recipient are low middle-income with a median household income range of \$20,000 to \$25,999 (1996 dollars).
- About one-third (34%) of CRC family caregivers of all ages are employed. Of those under the age of 65, the employed caregiver population is over half (53%).
- Caregivers provide an average of 73 hours of care per week--an average of 10.5 hours of care per day for a brain-impaired relative.
- Prior to contacting the CRC, most caregivers (58 %) had not received any help from other service agencies.
- Depression continues to be a pervasive problem for nearly six in ten (58%) of the family caregivers.

Most recently, the following key trends have emerged from our uniform, statewide assessment database comparing data on family caregivers in 1992 and 1997:

- *Caregivers are more likely to be caring for aging parents.* Although spouses are still the largest kin group, adult child caregivers increased from 36% in 1992 to 40% in 1997, while spouse caregivers fell from 51 % to 47% during the same time period.
- *The proportion of caregivers who also work outside the home increased.* Caregivers under age 65 (those most likely to be in the workforce) increased from 47 % to 53 % in 1997. Even more dramatic, those who reduced their work hours because of caregiving responsibilities at home soared from 18 % in 1992 to 43 % in 1997.
- *Caregivers served by California's CRC are increasingly ethnically diverse,* rising from 14 % non-white in 1992 to 18 % non-white in 1997.
- *Caregivers are less likely to receive adequate support from their own friends and family.* In 1997, 44% of caregivers said the help they received from their own family network was "far less than they need" compared to 28% who said the same thing in 1992.
- *Brain-impaired care recipients are more likely to be enrolled in managed care plans.* The proportion of brain-impaired adults enrolled in an HMO nearly doubled from 21% in 1992 to 40% in 1997.

Service usage continues to grow at CRCs as California families seek a variety of supportive services. Often, however, demand for services outstrips the limited resources at the CRCs. The following are highlights from the most recent service utilization database:

- More than 10,000 individuals were served by California's CRCs during FY 1996-97.
- The top four services at CRCs (beyond intake and assessment) were: 1) family consultation; 2) follow-up information & referral; 3) support groups; and 4) in-home respite assistance.
- The most common service package was family consultation with either follow-up information and referral *or* CRC respite assistance.
- Over 5,400 family caregivers completed the intake process, contacting a CRC for the first time. Nearly two-thirds (65%) completing intake went on to receive additional CRC services.
- On average, most family caregivers served at CRCs during FY 1996-97 received about three (3.2) hours of caregiver support services, beyond basic information and initial assessment (excludes

respite assistance).

- The average service use per family client across all CRC core services (i.e., includes those receiving respite and/or other services) was 21 hours during the fiscal year.
- A total of 774 family caregivers received CRC respite assistance in FY 1996-97. CRC respite clients received an average of seven hours of respite care per week at an average cost of \$234 per month (including an \$18 client copayment).

The need for **basic information continued to be the most** expressed by caregivers at intake followed by, emotional support and respite care. However, for caregivers who went on to receive the more in depth CRC assessment, emotional help (87%) and respite care (76%) were the top two needs.

Program Strengths

- **Not Disease-Specific Nor "Aging" Specific:** The CRC system has a broad focus on all adult-onset brain-impairing conditions. Twenty years of experience has shown that families caring for adults across diagnostic categories of brain impairments share similar concerns, common family problems, and corresponding service needs. Typical among the experiences of family caregivers, regardless of age or their relative's diagnosis, are: profound grief over the gradual loss of a loved one through a degenerative disease or sudden change as a result of a traumatic brain injury; physical and emotional fatigue due to nearly constant needs for care and supervision; financial strain, and often impoverishment; and stress from the multiple responsibilities of work, caregiving, and the needs of other family members.
- **The Caregiver is the Client:** FCA was the first program in the U.S. to recognize the family caregiver (rather than the impaired individual) as the client. FCA and its affiliate CRC system recognize that the care recipient's family caregiver needs assistance and support and a comprehensive range of services responsive to the caregiver's need. In essence, the statewide program recognizes the family caregiver as a legitimate consumer of long-term care services. While public awareness has greatly increased since the inception of our service system, it is imperative that we continue to support families who are the backbone of long-term care assistance in this country. It is estimated that families (not agencies or institutions) provide 80% of all long-term care to functionally-impaired loved ones. Our data indicate that California families using CRC services provide an average 73 hours of care assistance per week-more than a full-time job.
- **The Focus is Consumer-Directed:** As mentioned earlier, CRC services are consumer directed. CRC staff understand that their role is to inform and support, but that care decisions remain the purview of the family caregiver. Families participate fully in planning and service delivery issues. Families retain maximum control over care decisions. This concept has been heavily supported by the disability community for years. Recently, however, one of our research studies examined consumer choice among in-home respite users at nine CRC sites (Friss Feinberg & Whitlatch, 1996). Among the most significant findings was that caregivers preferred *direct pay* respite (where the family caregiver receives a cash subsidy to hire an independent provider) more than two to one over agency-based respite care. Among the advantages of this option is the fact that families can afford more care, since the hourly cost of hiring an independent provider is lower than receiving assistance from a home care agency.
- **Package of Support Services, Not Respite Only:** Research has shown that a package of supportive services including ongoing, targeted education and mental health interventions *in addition to respite care* for family caregivers helped delay institutionalization of persons with

dementia by nearly a year (Mittelman et al., 1996). CRCs offer a full range of caregiver support services, not just information and referral, not just support groups, and not respite alone. The service options allow families to address the multiple needs for emotional, practical, and financial support.

- **Statewide Resources Consultant (SRC) Function:** The cohesiveness of the CRC system network is fostered by the SRC role. A primary function of the SRC is to provide technical assistance to the CRCs. This assistance builds a strong statewide CRC network and is a uniform yet flexible approach to meeting the changing needs of family caregivers. Family Caregiver Alliance, as the SRC, works with the CRC sites to promote program development; expand and refine service delivery; analyze data, including client-based and service utilization trends; and provide ongoing technical assistance to CRCs on clinical skills building; current policy and research updates; uniform information development; assistance with data collection and reporting; and systemwide strategic planning. Collectively, our technical assistance has addressed program design (FCA wrote the original CRC *Operations Manual* of policies and procedures for the CRC system and, under the direction of the Department of Mental Health, has continuously updated it to meet the changing needs of the sites); start-up (e.g., understanding the client population, developing job descriptions, setting up office procedures, establishing service subcontracts, providing initial outreach, establishing an advisory committee, establishing program and fiscal reporting requirements, etc.); program information (e.g., preparing a statewide brochure, fact sheets, educational displays); on-going program and service implementation (e.g., marketing and fundraising techniques, software development for client tracking; implementation of a uniform assessment tool and process, establishing procedures for when to "open" and "close" client cases; refinement of procedural information for community coordination, services and administrative areas); and strategic planning to help shape the continuous development of the CRC system, and provide staff support to implement system-wide goals. Additionally, the following functions are also designated to the SRC:
 - Serve as the Statewide Information and Technical Assistance Clearinghouse on adult-onset brain impairments and caregiving issues.
 - Work closely and coordinate with other statewide organizations which serve brain-impaired adults, their families, and caregivers.
 - Develop and conduct training appropriate for families, caregivers, service professionals, advocacy organizations, educational institutions.
 - Conduct conferences to assist families, caregivers, service professionals, advocacy organizations, educational institutions, business associations, community groups, and the general public in order to enhance the quality and availability of high-quality, low-cost care and treatment for brain impaired adults.
 - Assist the Department of Mental Health in identifying and securing increased federal financial participation and third party reimbursements.
 - Conduct Social policy research.

Make recommendations to the California Department of Mental Health and the Secretary of Health and Welfare for a comprehensive statewide policy to support and strengthen family caregivers.

On-Line Information Technology: Application of information technology is starting to transform the way that older adults, families, caregivers, and practitioners find information, make decisions, connect with experts, gain mutual support, and transact business (Kelly, 1997). FCA operates an award-winning (1998 Mature Media Award) website; www.caregiver.org ; with an estimated 7,500 visits per day. The site incorporates a number of innovative features for users including over 30 on-line fact sheets, information on California's CRC system, research highlights, policy issues and advocacy alerts, book reviews, community events, and links to other notable sites. An online information request form is used to assist inquirers by asking them to provide some basic information about their caregiver situation. An on-line support group allows caregivers in disparate locations to share information and mutual support. As well, FCA is working to develop an Internet-based information and support system via a secure Internet site integrated with several CRC sites.

Barriers In Serving Family Caregivers

- **Outreach/Getting the Word Out:** We understand that long-term care and dementing illnesses are not foremost on everyone's mind. Yet when a family faces a devastating diagnosis, or the sudden stroke of a loved one, it become a very personal and immediate need; they desperately want information and help. Thus, outreach is an ongoing challenge for the CRCs. Publicity is constantly sought in the print media, radio and television. And, access via the World Wide Web has brought CRC services and information resources to countless families. CRCs report routinely that high profile media campaigns bring in new clients. Gaining access to underserved communities and all those in need remains a primary objective at all CRCs.
- **Reluctance to Use Services:** Research has shown that family caregivers are reluctant to use support services, particularly respite care. CRCs address this issue by working with families to overcome any concerns about leaving their loved one in another's care. Support services such as caregiver retreats, psychoeducational classes, or support groups enable caregivers to meet their peers and decrease their isolation. Learning what has worked for others can encourage them to take advantage of additional CRC support services. Moreover, weekend respite camps are an excellent opportunity to allow caregivers to "try out" a brief period of respite. Finally, ongoing contact with and encouragement from CRC Family Consultants over time can persuade caregivers to value their own well-being enough to accept help.
- **Diversity/Language Barriers:** California is home to millions of immigrants and is becoming increasingly ethnically diverse. Large populations of Latinos, African Americans, Filipinos, Chinese, Vietnamese, and other Asian populations (among many others) present real challenges in reaching out to these communities in a culturally appropriate manner. CRCs continue to emphasize targeted ethnic outreach programs, and to work with other community-based groups to reach underserved minority communities. A number of the CRC fact sheets have been translated into Spanish and some materials have been translated into Chinese. On a regional level, virtually all CRCs have bilingual and bicultural staff and have worked to gain access to communities including Native Americans, Vietnamese, Hmong, Chinese, Mexican and Central Americans, inner-city African Americans, and many others.
- **Rural Areas:** CRC service regions cover the entire state of California including vast rural areas. Large service regions for each CRC site provides numerous challenges for reaching and serving isolated communities. To assist rural caregivers, CRCs play active roles in coordinating with other local task forces and committees and many take on leadership positions in promoting community program development for such services as adult day care centers, residential facilities, day programs for brain injury survivors, and other services needed at the community level. CRCs facilitate a variety of support groups in rural areas-often the only support service available for miles, and promote education of both families and service professionals through annual rural trainings on Alzheimer's disease, which are

cosponsored with other state agencies and community-based organizations.

- **Funding:** Inadequate funding is a problem that plagues most state programs and human services agencies. CRCs have worked to develop a service package which is cost effective, with strategies for reaching out to and serving caregivers, even as they wait for CRC subsidized respite care (e.g., with weekend respite camps). Nonetheless, currently, **more than 3,000 family caregivers are on respite waiting lists at CRCs in California.**

Just recently, however, we have had the best news that any state-funded program can have. Last month, Governor Wilson signed a \$4 million budget augmentation for the 11 CRCs and the SRC. After a nine-year period of no growth in the state general fund, the state appropriation for the CRC system will nearly double from \$5.047 million in FY 1997-98 to \$9.047 million in FY 1998-99. This funding will be used to provide respite to many of the families currently on waiting lists and to expand other support services to serve more family caregivers.

On behalf of Family Caregiver Alliance and California's Caregiver Resource Centers, thank you for the honor and privilege of testifying before you today.

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